

Written Testimony of  
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Joint Committee on Public Health

**SB 654 An Act Concerning the Availability of Prescribed Antiepileptic Drugs**

Good morning!

I'd like to thank you for your time and for the opportunity to speak on behalf of Senate Bill #654, An Act Concerning the Availability of Prescribed Antiepileptic Drugs. I've had epilepsy my entire life. It's been an ongoing struggle involving surgery and multiple medication trials. It's always been a little like walking a tight rope for me finding the right medications to take at the precise dosage. I've collaborated with teams of doctors throughout the Northeast and am thrilled to be seizure free. I take one day at a time following my medication regime - taking my meds at the correct time and in the precise dosage.

Anti-seizure meds can be extremely expensive. Just this past year my medication cost nearly \$12,000. Fortunately many generic anti-seizure medications are now available and much less expensive than brand name meds. But it's not that simple. Not all generic drugs are the same. The active agents or anti-seizure agent can differ by up to 20% among different manufacturers of the same drug. This variability of up to 20% is enough to potentially cause a seizure injuring the individual and possibly the people around him.

Imagine being at a job interview. Just close your eyes for a moment. You're at the job interview. You start feeling light headed. The next thing you know-you're waking up in the emergency room with a nurse putting the IV patch in your arm. Slowly in disgust you realize you had a seizure and you'll be in the hospital for hours, waiting for the doctor, getting blood tests and who knows what else. Once again you're back at square 1. You're humiliated, disgusted and discouraged. And you have a pretty good hunch you don't stand a chance of getting that job.

But worst of all this is completely avoidable. If patients and doctors are informed and provide consent for the manufacturer of the generic drug to be switched, we can avoid these situations. One boy in Georgia was having a few seizures a day. All of a sudden it increased to hundreds a day. The dad could not imagine what had happened. He spoke to the doctor and they realized the manufacturer of the generic drug had been switched. He went back to the original medication and his seizures were reduced. It is clear that people with epilepsy do not respond the same way to different versions of generic drugs.

We can close this gap. We can work together to ensure doctors and patients provide consent before there is any switch in the manufacturer of generic drugs. We live at the mercy of many variables. Each one of us faces a challenge. My challenge is epilepsy. I wake up every day taking my medication and I don't need another variable to throw in the mix. As with all patients

with epilepsy it has taken years to refine the exact dosage of all of the medications I take. No one with a seizure condition can risk even the slightest change in the active agent of their meds. On a final note this bill has far reaching implications. It will reduce the risk of seizures by using generic meds from manufacturers which are approved by doctors and patients, and will reduce avoidable medical costs such as ambulance and hospital expenses.

At a time when we are plagued with mounting medical expenses we should take every measure to provide preventive medical care and at the least protect patients from avoidable medical crisis such as seizures. Passage of this bill is a win win situation. It will reduce risk of potential seizures which can injure the patient and people around them and minimize avoidable medical expenses. For people who struggle like me with epilepsy it is a travesty to place their life at risk by unknowingly changing manufacturers of generic medication.

Thank you for your time and I ask you to please vote for Senate Bill #654.